



Gastroschisis

Information for parents and carers



Your baby has been diagnosed with a condition called gastroschisis. We understand that this may be a worrying and stressful time for you. This leaflet explains a bit more about this condition.

Key messages

- Gastroschisis is a condition where your baby's bowel develops outside the tummy
- Your baby will need an operation
- Most babies survive to become healthy adults

What is gastroschisis?

Gastroschisis is a defect that occurs in the wall of a baby's abdomen (tummy) when they are developing in the womb. It happens in the third month of pregnancy. The hole is to the side of the umbilical cord. The baby's bowel comes through this hole and continues to develop outside the baby's abdomen and float in the amniotic fluid (the water around the baby). Figure 1 shows this. After the birth, the bowel needs to be returned to the abdomen to protect it from damage. Your baby will need an operation for this.



Figure 1

How common is gastroschisis?

Gastroschisis occurs in about 1 in every 4,000 babies in Scotland. Around 20 babies are born with gastroschisis in Scotland each year.

Could my baby have any other problems?

Most babies born with gastroschisis do not have any other abnormality. However, in Scotland, about 1 in 20 babies born with gastroschisis have a blockage (atresia) of the bowel. This might be suspected on scans during pregnancy if the bowel looks swollen, but it can only be diagnosed after your baby is born.

A further 2% of babies with gastroschisis can have more complex problems.

What will happen during pregnancy?

Gastroschisis is often found during pregnancy. It is most often diagnosed at your booking scan but can be found at a later scan. If your baby has gastroschisis you will be referred to your regional fetal medicine centre. There, a fetal medicine specialist will carry out a detailed ultrasound scan and you will be able to discuss your baby's condition with a neonatologist (a doctor who looks after newborn babies) and a paediatric (children's) surgeon.

Your pregnancy will be monitored closely and you will need regular scans to make sure your baby is growing well and to look at the bowel to make sure it looks healthy.

What happens when my baby is due?

The neonatal surgical centres in Scotland where babies with gastroschisis are cared for are Royal Aberdeen Children's Hospital; Royal Hospital for Children and Young People, Edinburgh; and Royal Hospital for Children, Glasgow.

Your delivery will be planned for around 37 weeks in the closest maternity unit linked to these surgical centres. In Scotland, more than half the babies with gastroschisis are born before this time (usually between 34 to 37 weeks) due to premature labour. If your labour does start early and there is no time to transfer you to one of these units, your baby will be transferred by a specialist neonatal transfer team soon after they are born. About half of mothers expecting a baby with gastroschisis have a vaginal delivery, the other half have a caesarean section.

What will happen after birth?

General care

There will be a team of nurses and doctors to care for your baby as soon as they are born. Your baby will be kept warm and the bowel will be protected by cling film or a special clear bag. A nasogastric tube will be put down your baby's nose into their stomach. This tube keeps the stomach empty. Your baby will be moved to the neonatal intensive care unit. You will be able to see, touch and speak to your baby and take photographs. Your baby will need special attention to protect their bowel, which can be fragile, so you may not be able to cuddle your baby at first. A drip will be put into a vein to give your baby medicines and fluids and to take blood samples.

Surgical care

The paediatric surgery doctors will meet you after they have examined your baby. They will explain what they believe is the best way to get the bowel back into your baby's abdomen. You will be asked to sign a consent form to show that you understand and agree to the operation.

Around two-thirds of babies who are born with gastroschisis have the bowel placed in a 'silo.' This can be done on the neonatal unit or in the operating theatre (under an anaesthetic). Figure 2 shows a silo in place.



Figure 2

A silo looks like a clear plastic pouch and the bowel can be seen inside it. It protects the bowel and, over the next few days, the bowel is gradually returned into the tummy. This usually takes between three and seven days but can take longer. Once the bowel is inside, the silo is removed and the hole in the abdomen is closed with a dressing or stitches. After this is done, you will be able to start having cuddles with your baby.

In some babies (around a third), the bowel can be placed back into the tummy on the first day of life. This is usually done in theatre under an anaesthetic, but can also be done on the ward. Again, the hole is closed with a dressing or stitches.

Due to the nature of gastroschisis there is no other alternative than to look after your baby in this way.

Within the first few days or weeks of life, your baby will not be able to feed so will need a long-term drip. This is called a PICC or central line, and will be put in your baby's arm, leg or neck. This will allow your baby to have special fluids into the vein for nutrition until your baby starts managing milk feeds given into the stomach through the nasogastric tube.

If your baby has a blockage in the bowel (atresia), the surgeon will discuss the best way of dealing with this. While the blockage is there, your baby cannot have any milk feeds. There are different options for surgery depending on where the blockage is.

What happens next?

The main issue for babies born with gastroschisis is that the bowel can take a while to start to work normally. The average time for starting feeds is around nine days. The doctors and nurses will monitor your baby closely and decide when to start giving your baby some milk into the stomach down the nasogastric tube. We will then see how much milk is staying down, and gradually increase the milk. The average time to being on full milk feeds is three to four weeks.

If your baby has a blockage in the bowel, it will take much longer for them to start having milk.

Around a third of babies with gastroschisis can develop problems with infection of the wound, bowel or central line. Sometimes another operation is needed due to this problem.

What can I do to help my baby?

There are lots of things that you can do to help your baby including cuddles, positive touch and reading to them. The staff will also support you to become partners in your baby's care so that when you feel comfortable you can help with things like nappy changes and nasogastric tube feeding. We call this approach family integrated care.

Breast milk is the best milk for all babies, especially babies born with gastroschisis, and many mothers find this a positive way to help their baby. However we recognise that not everyone chooses this option and other milks (including donated breast milk and specialist formula) are available.

What is the likely outcome for my baby?

Most babies born with gastroschisis survive and leave hospital feeding normally. We expect all these children to become healthy children and adults. A small number of babies born with gastroschisis can have longer-term problems if their bowel cannot absorb feeds properly.

How long might my baby be in hospital?

You should expect your baby to be in hospital for four to eight weeks, although this can vary considerably. Although the early care of your baby will be in one of the surgical units, it may be possible to move your baby to a neonatal unit closer to your home once they are stable. The surgical team will speak to you about this.

Where can I get further information and support?

The fetal medicine, paediatric surgical and neonatology teams will be able to answer any questions that you have during your appointments.

In 2018, the Surgery for Conditions Affecting Newborns in Scotland (SCANS) was formed. This is a national network of doctors, midwives, nurses and parents. It was set up to produce standards of care so that you and your baby get the best treatment. You

can find more information at www.scans.scot.nhs.uk. We have listed other support groups below.

Other useful sources of information

www.arc-uk.org

www.gov.uk/government/publications/gastroschisis-definition-screening-diagnosis-treatment

Facebook Gastroschisis Support Group

www.facebook.com/groups/348202808541419/

SCANS collects anonymised data (information that you and your baby cannot be identified from) about the different conditions we treat. We use this information to plan and deliver services to children with these conditions, understand how we can improve patient care and provide it in the best way possible for all of our patients. All information is handled securely and confidentially by NHS staff and we do not share it with outside organisations. If you have any questions or concerns about the information we collect or your data protection rights, please email nss.scans@nhs.scot.

You can find more information about how the NHS handles your personal information at [NHS Inform](#).